PRESENTATION TO GOVERNMENTAL OVERSIGHT
HOUSE SUBCOMMITTEE ON
HSB 302

I. Opening Statement:

- Preface:
    - My name is Sally Reavely and I am here today to speak on behalf of the Iowa Bar Association.
    - I practice health law and represent health care providers such as those who you have or will hear from today: hospitals; nursing homes; home health agencies; and physician and physician groups. I could wear four hats today: Caregiver, licensed professional (RN); caregiver, family member for deceased parents; individual with advance directive; and attorney.
    - Today I wear only the attorney, hat but it is hard to separate as the emotions run high in this area
- I am here also representing a special committee appointed by J. C. Salvo, President of the Iowa State Bar Association. The other members of the committee are Cynthia Moser, or Sioux City; Diane Kutzko, of Cedar Rapids. Both are also practicing health care attorneys.
- We were charged with review of the legislation; monitoring of the legislation through the legislative process; providing information to the Legislature on issues; reporting to the Board of Governors regarding our recommendation on the legislation.
- Are here today to present our comments on HSB 302. This is not the official position of the Bar Association. That will occur at its December Board of Governor's meeting at which time the Legislative Agenda will be set. If HSB 302 is still in its present form at the time of our recommendation, we will recommend the Bar Association go on record and oppose HSB 302.
- Our oppositions cover many grounds, some of which I will speak about today. Time is limited so I will speak briefly, but Ms. Moser, Ms. Kutzko and I would be glad to provide additional information should the subcommittee need such.

II. Grounds for Opposition

- <u>The Current Law Works and Upholds an Individual's Right to Make End of Life Decisions.</u>
    - History of Current Law
        - Chapter 144A was passed in 1985 but did not include hydration and nutrition in its definition of life sustaining procedures.
        - Increasing concerns about liability prevented doctors from doing what they had done for many years , decisions were made by patients, their families in consultation with their physician who provided sound medical advice and provided information so an informed decision could be made.
        - County attorneys were taking a hard line on the issue because there was no authority to permit withdrawal of artificially provided nutrition and hydration – a number were on record as threatening to prosecute as murder charges.
        - Families were caught in the middle, frustrated and distraught not able to implement what they knew were the dying family member's wishes
        - Doctors and hospitals were increasingly in a bind and not able to honor patient autonomy.
        - The *Cruzan* case brought issue to the fore.
        - Coalition of Iowa Medical Society, Iowa Bar Association, Iowa Hospital Association and others began addressing issue through discussions, education, and ultimately drafting legislation.
        - The process had the participation of a broad spectrum of disciplines, including religious leaders (notably the Catholic Church, represented by Tim McCarthy)

- The first step was to draft a durable power of attorney statute (91 Acts).

- Significantly, it passed 85-10 in the house and 46-2 in the Senate.

- Then, in 1992, the same coalition worked on the amendment to the living will statute (92 Acts), which included artificial nutrition and hydration. It passed 82-15 in the House and 43-1 in the Senate.

- Great care was taken to conform the definition of terminal condition to the most up-to-date medical thinking at the time (which appears to still be good medicine - impossible to draw a bright line). The definition was either taken from or reviewed by the American Academy of Neurology.

- After passage of the bills, the same coalition spent time on education in the medical, legal communities as well as in communities educating individuals and professionals.

- The issues which HSB 302 purports to resolve were those considered over the entire process, allowing each constituent to provide their positions, suggestion. In the end there was unanimous consensus that the proposed legislation was medically, legally, and ethically sound and in the best interests of the citizens of Iowa.

- The bottom line is that it <u>works</u>. In the years since passage, there have been no allegations or cases of abuse - no lawsuits arising from the misuse of the statute.

- <u>This Bill Would Turn On Its Head A Patient's Right To Direct and Control What They Want To Do At End of Life</u>

    - The Bill would insert a "presumption" that a person who is unable to make medical decisions for themselves wants to be maintained on artificial nutrition and hydration.

    - Current law (144A.11(4)) specifically states that there is <u>no</u> presumption against a person who has not executed a Living Will. This Bill directly contradicts current law.

- The Bill would take from family members the time honored decisions that courts have recognized for decades (including the Iowa courts) that end of life decisions and treatment decisions for adults who are unable to make their own medical decisions are made between family members and physicians. *Morgan v. Olds,* 417 NW. 2d 232 (Iowa 1987).

- The hierarchy of family decision makers, recognized for decades, has been codified in 144A.7 and is the following: agent appointed under a Health Care POA (144B); a court appointed guardian; the spouse; an adult child or majority of adult children; a parent of the patient or both parents if available; an adult sibling.

- This Bill directly contradicts current law regarding hierarchy of substitute decision makers and would give a litany of persons the right to challenge the patient's prior advance directive regarding artificial hydration and nutrition. Iowa Code § 144A.7.

- This Bill would undermine the patient's specific wishes by allowing the physician or health care facility to ignore his/her obligation under current law (144A.8) to transfer the patient to another physician or health care facility when the physician or health care facility did not want to comply with the Living Will. Executing a Living Will or Health Care POA was intended to provide an individual with the comfort, certainty and security of knowing that their wishes regarding medical treatment and end of life decisions would be carried through with. If this Bill is enacted, a person executed a Living Will or Health Care Power of Attorney would have no assurance that their wishes will be followed

- This Bill makes the Health Care POA of limited, if of any usefulness in an end of life situation. The purpose of the Health Care POA is to provide a person the right to appoint an agent who would carry out their wishes. It is intended to provide flexibility for the individual to be able to discuss with the agent the individual's wishes which may change over a period of time depending on many circumstances. As a result, the majority of the time individuals who execute a Health Care POA do not make specific statements in the POA but instead discuss what they want with the agent(s). This Bill would totally undermine the individual's intent to have someone they appoint make decisions for them. Without specific statements in the POA, those listed in the Bill could

challenge the right of the agent to make decisions for the individual.

- This Bill will require health care providers to be legal experts in interpreting a Living Will or Health Care POA. Section 2 of the Bill prohibits any person (including designated agents under a Health Care POA) from deciding whether to withhold hydration and nutrition unless that person finds an exception under Section 3 of the Bill: finding there is "clear and convincing evidence" exists that the person gave express and informed consent to withdraw or withhold nutrition and hydration. These are legal terms and they are in the purview of the courts to determine what is "clear and convincing evidence". Health care providers are not legal scholars and they clearly are not judges charges with interpretation of facts versus provision of the law. Health care providers will not act because they cannot act under this Bill. Patient's right to have their end of life decisions followed will not be complied with.

- This Bill creates uncertainty as to the effect of currently effective Living Wills and Health Care POA's. Although the Bill states that Living Wills and Health Care POA's will not be "invalidated" by this Bill, it is clear there would be two different laws against which health care providers will be asked to make decisions regarding Living Wills and Health Care POAs. Experience has proven, health care providers will not act where there are any questions as to the legality of advance directives. Implementation of advance directives will, to a large extent, come to a stand still until each one is reviewed by legal counsel, delaying and likely undermining the intent of the individual. <u>As a health care attorney, I will have to advise my clients, hospitals, nursing homes, hospices, home health agencies, physicians to have all advance directives reviewed by legal counsel before giving effect to them.</u>

- <u>Example:</u> I want to share with you an example of what will without a question occur, and probably with in a short time of this Bill being enacted. Patient is terminal and currently has a gastric feeding tube inserted and an IV for hydration. Patient is unable to swallow and following surgery. Surgery did not correct nor lengthen the life expectancy. Feeding tube is not only prolonging the dying process. Patient is competent adult and instructs his physician to withdraw the feeding tube and the I.V. There are several family members in attendance who hear this. Before the physician can have the feeding tube removed, patient becomes

comatose and it is anticipated will not regain consciousness. A good intentioned nurse doesn't believe in withdrawing feeding tubes so brings an action under Sec. 4 of the Bill to secure a court determination on whether this person's feeding tube should be removed.

- This is not a far fetched example. This Bill would allow this blatant denial of a person's right to make medical decisions and refuse treatment. The patient's family could not stop this court action and the patient would have to be maintained on the tube feeding until this could go to court and until all appeals were exhausted.

- There Will Be Legal Challenges; It Is Just Question of When.

  - Common Law and Constitutional Right to Refuse Treatment Challenges: The right to refuse is based on (1) the common law right to freedom from nonconsensual invasion of bodily integrity; reflected in the informed consent doctrine and the law of battery; and (2) the constitutional right to privacy.

    - Our own state Supreme Court was a leader is recognizing these rights in a 1910 case where the court recognized that a patient's right to make decisions concerning medical care necessarily includes the right to decline medical care. *White v. Chicago & N.W.Ry. Col, 124 N.W. 309 (Iowa 1910).*

    - Additionally there is a long line of federal and state cases, including U.S. Supreme Court cases that have found that there is a constitutional right to privacy which includes the right to make medical decisions including the right to refuse medical treatment. This right was also recognized as a basis of care in the *Quinlan and Saikewicz* decisions even though the patients in both cases were unable to express their wishes. *In re Quinlan*, 355 A.2d. 647 (N.J. 1976); *cert. denied sub nom. Garger v. New Jersey, 429 U.S. 922 (1976);* superintendent of *Belchertown v. Saikewicz, 370 N.E. 2d 417 (Mass. 1977).*

    - While a state has recognized interests that may override a person's right to make their own medical decisions, those are significantly limited and in cases where competent individuals have executed advance directives and/or

made clear their intention regarding treatment and end of life decisions, those State interests are weakened and yield to the individual's rights. *See In re Quinlan; Saikewicz.* The *Saikewicz* court stated there is "substantial distinction between curable afflictions and conditions for which treatment can only briefly extend life". The *Saikewicz* court concluded:

- "The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice."

- These line of cases were extended to the "incompetent", person who is unable to make decisions on their own behalf but who, when competent, let their wishes regarding treatment be known whether by a written document such as a Living Will or through appointment of an agent, through the Health Care POA. This State has recognized that by enacting 144A and 144B as well as including the time honored and court recognized hierarchy for substitute decision makers where no substitute decision maker is appointed.

o Other Legal Challenges to the Bill Language.

- This Bill is poorly written

  - Definitions are ambiguous and do not comport to current law e.g. " nutrition as defined would include food and water by mouth. "Hydration " is not defined at all.

  - The name of the Bill is offensive and inflammatory indicating that Iowan's are "starving" and "dehydrating" disabled individuals. What is intended by the term other than to inflame? Is a disabled person under this Bill a "person legally incapable of making health care decisions"? To my knowledge there is not similar definition in Iowa or Federal law defining disability in that manner. In fact this would do great injustice to the American's With Disabilities Act and the

Rehabilitation Act, both of which health care providers must comply with on a daily basis.

- The "presumption" created under the Bill will conflict with the "no presumption" language under 144A and 144B which will created court challenges to interpretation of these statutes.

- The imposition of a court into the current process conflicts with the hierarchy under 144A and will be challenged as unenforceable since the two statutes would be in conflict.

- Questions will be raised and litigated as to the "immunity" provisions contained in 144A.9 and 144.9 and if they are pre empted under the new law.

- This Bill makes no distinction between nutrition and hydration provided parenterally or by intubation and nutrition and hydration provided through the gastrointestinal tract, e.g. by mouth. *See* Section 2. This is absurd in that no one can withhold food and water that a person could consume by mouth. At a minimum that would amount to dependent adult abuse under Iowa Code § 235B and in the worst case scenario, homicide if the person died. Current laws already protect against those scenarios.

- This Bill will be challenged by family members who have the right to act as the patient's surrogate under Iowa law. And this Bill will not prevent the Terry Schiavo case. Instead, by enacting this Bill there will be more rather than fewer court cases.

IV. Footnotes.

- Current laws already protect patients who are unable to make treatment decisions for themselves.

  - (1) If the patient has executed a Living Will, the treating physician must certify the patient is in a terminal condition and must also determine that the individual cannot make their own

treatment decisions before giving effect to the Living Will. The patient can always revoke the Living Will in any manner in which they can communicate their intention to revoke.

- (2) A person who has appointed an agent under 144B has the protection of the courts if someone questions that the agent is making decisions in compliance with the patient's wishes. The court can always be petitioned to review the case.

- (3) Dependent Adults are already protected under Iowa law from abuse. Iowa Code § 235B. Individuals who believe that a "dependent adult" is being abused can report to the Department of Human Services and they will investigate and have the authority to enforce laws to prevent abuse if such is the case. A dependent adult would include individuals in a health care facility. This current Bill would add nothing but another layer and conflicting laws which would not protect dependent adults any more than the current law.

- Federal law recognizes a person's right to make advance directives through the Patient's Self Determination Act as passed as part of the Omnibus budget Reconciliation Act (OBRA) of 1990. This law requires health care providers under Medicare and Medicaid to maintain written policies and procedures relating to living wills and advance directives. They are required to provide written Information about Iowa advance directive laws and ask if a person has an advance directive. They are to assure compliance with Iowa's advance directives laws and provide education on advance directives. A "patient's self determination" is of utmost important to the federal government as shown by its requirements under M/M laws. HSB 302 would be in direct opposition to the Federal initiative to promote a patient's right to self determination.

- Even infants who are incompetent to make their own decisions would have more rights under Iowa and federal law than competent adults under this Bill. Amendments to the Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101 through 5106h, defines "life sustaining" procedures to include (1) withholding or withdrawing of hydration and nutrition when it would be used for an infant who is chronically and irreversibly comatose; or (2) the treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions or (3) otherwise be futile in terms of the survival of the infant or the provision of such treatment would be virtually futile in terms of the survival of the infant and treatment itself under such

circumstances would be inhumane. This law, and corresponding Iowa law, does not give non family members, caregivers, etc. the right to go to court to prevent the withholding or withdrawing of such procedures. As with adult abuse, this would be enforced by the Department of Human Services. Iowa Admin. Code § 441-175.21. Do not competent adults have the same rights as newborns when it comes to end of life decisions?

IV. Summary

- This Bill should not be moved out of Subcommittee and/or enacted into law.

- This Bill will a set back of twenty years or more in Iowan's right to privacy and right to make advance decisions as to their treatment.

- This Bill will interject persons who have no interest in a person's well being or life and who have no legal right to make treatment decisions for that individual into the treatment decision process.

- This Bill will create a back log of court cases in enforcement of the provisions and in challenges to the Bill itself.

- Time has shown that Iowa has laws that work and that have taken into consideration an individual's right to self determination.

- Iowa has had no significant challenges to these laws and they work.

- This Bill is not needed and will only create uncertainty and take away from competent adults their constitutional right to make treatment decisions and to have the comfort to know that those decisions will be followed by their surrogate decision makers and their care givers.